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The American College of Cardiology's National Cardiovascular Data Registry (NCDR) is one of the largest clinical data repositories in the United States. In 2400 hospitals and in continuous operation for over a decade, the NCDR manages 6 clinical registries with over 10 million patient records. While the rigorous interrogation of this data set generates near-continuous scientific insight, the NCDR prides itself on a highly pragmatic mission—providing the feedback hospitals and individual physicians need to improve the quality of care delivered to patients.

The NCDR's experience with the nation's first prospective office-based cardiac quality improvement registry is particularly germane to the Committee's work. The Improving Continuous Cardiac Care or IC3 Program was launched in 2007 with the following two-fold purpose: to close the quality gap between intention and achievement in outpatient cardiac care and to prepare practices to thrive in a performance-based reimbursement system. IC3 is designed to help clinicians deliver scientifically sound, highly personalized care to every patient, every time using an embedded systems approach we are beginning to call "QI Inside". Over 180 practices now participate in the program, representing nearly 700 practice locations and thousands of physicians. Collectively, these practices have submitted over 350,000 patient records in well less than a year of active data collection.

The foundation of the IC3 Program is science, the clinical practice guidelines from which performance measures are derived. IC3 collects, at the point of care, the necessary data elements to construct 29 core performance measures that cover the major cardiovascular conditions—coronary artery disease, hypertension, heart failure, and atrial fibrillation, as well as referral to cardiac rehabilitation, a valuable and vastly underutilized therapy. Participants receive quarterly actionable reports at the individual clinician, practice, and national levels with benchmarking and clearly identified opportunities for improvement. On behalf of participants, IC3 can submit data to payers, including Medicare and the PQRI program. It is an additional goal of the Program to capture and share best practices of high performers to accelerate learning and care improvement.

An early lesson from the Program is that each practice is unique. Our approach therefore was to offer a variety of "solutions" for data collection: paper, web-based tool, and EMR-vendor collaboration to embed our data elements in their products. Our first adopters and about one-third of current participants collect and submit data on paper. As tedious as this approach sounds a definitive benefit to busy practitioners is the decision support provided by the data collection tool. We have since observed that the data coming from the paper practices is the highest quality data we have to date. However, we quickly realized that the widespread adoption of IC3 would require a more streamlined data collection approach with minimal disruption to workflow. As of August of this year, the vast majority of records are pulled directly from the practice's EHR system using a

proprietary data mapping and extraction solution. While we are highly confident in this solution, there are still gaps in the data. Many of those gaps are resolved through complicated data interpolations requiring additional expertise, time, and patience and some will require the IC3 program to deploy additional technology solutions. Let me provide examples of two different types of data gaps and then use them to illustrate our conclusions.

The easier issue to understand, if harder to solve, is simply the absence of data. Complete data absence has two root causes—a knowledge gap on the part of the physician or EHR incapacity to record. We can weigh in to help close the knowledge gap, but struggle mightily with the EHR issues. We are finding this problem to be particularly acute in atrial fibrillation, where we would estimate that 90% of the data elements in 90% of the practices are not being collected. For example, we have yet to find one practice that electronically stores INR results and the associated dosage modification for warfarin management. Even worse, many EHRs do not store the actual date of cardiac events, making it difficult to impossible to assess whether a patient is receiving the optimal post-event pharmacological therapy.

The more common challenge, however, is poorly structured data. While we are making progress in ferreting out or probabilistically matching data, it is resource and time intensive. To continue with the date of event example detailed above, even physicians and EHRs that do capture this information often do it in an unstructured format—meaning free text in comments fields. This is actually a common data storage technique for EHRs, essentially making these systems little more than electronic analogs to paper charts. In this scenario, we are deploying automated text searching capabilities to find and capture relevant dates.

In other situations, we are moving beyond the EHR itself and interfacing with a wide variety of practice IT systems. For example, since EHRs very rarely record insurance information, we map to practice management systems to determine whether patients are commercial, Medicare fee-for-service, or Medicare Advantage patients for PQRI reporting. To determine whether a PCI deployed a bare metal or drug eluting stent, we analyze billing systems for the brand name of the stent and then crosswalk to stent category. Even just determining whether a patient record is for an inpatient or outpatient visit requires writing additional complex logic.

These problems are compounded by the fact that this exercise must be repeated for each and every practice. The degree of variation between EHR systems is bewildering. Of course, each vendor has its own data storage structure. Then these “standard” configurations are often modified by vendors multiple times within even a single year. Finally, most practices highly customize not only the physician-facing templates and workflow, but the underlying data structure. While there is logic to each one of these variations, taken together they almost look random. We expect that as our experience improves with each system, data mapping will become a more efficient process for the IC3 program. As of now, we have successfully mapped and extracted from NextGen, GE Centricity, GE Logician, AllScripts, and GEMMs.

What can we conclude from our experiences with IC3? First, there is presently insufficient standardization within practices and EHRs—both in terms of what should be collected and how it is stored—to allow for the efficient exchange of clinical information and assessment of performance on a national scale. Second, the standards that do exist for structuring data—such as CCR and CCD—are also insufficient. Not only do most of them lack the detail necessary to construct scientifically valid performance measures, but there are so many of them, each further customized by the various HIT vendors, that even calling them standards is misleading. IC3 explored, but ultimately had to abandon, working within an established clinical data standard for that reason.

The ACC's IC3 Program has been capable of jumping these hurdles because of its single-specialty focus and the ability to date to expend significant resources on the custom integration of each and every practice. Obviously the goal for the nation is a highly replicable system with low impact on workflow, a reliable and efficient method for complete and accurate performance measure calculation, timely generation and delivery of actionable reports, and all this, at an affordable price. We deeply appreciate the work of the Committee and have confidence that you will help us all achieve this goal.